

Title: Agency collaboration and effective continuity of care for HIV-positive pregnant women

Health department/organization: Florida Department of Health, Bureau of HIV/AIDS

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Goals: Linkage to and maintenance of care for HIV-infected women

Program type: Case management

Collaborators: Other HIV/AIDS program staff; HIV/AIDS surveillance; MCH partners; other health department

Background/Objectives

Florida's Enhanced Perinatal Surveillance data for 2002 – 2004 indicate that 65% of women who delivered an HIV-infected infant knew their positive HIV status either prior to or during pregnancy. For many HIV-positive pregnant women there may be barriers that prevent them from accessing adequate health care services such as a lack of health insurance or Medicaid coverage, inadequate transportation to appointments, homelessness or domestic violence situations. Women who are abusing substances may deliberately avoid the service system out of fear of being reported to the authorities and having their infant removed. Some women may access one part of the system, only to be denied services and subsequently drop out of care. Florida has multiple communities with excellent service systems for pregnant women that are effective and coordinated between several agencies. However, in many areas of the state there is no 1 agency or program responsible for assuring full continuity of care (from pregnancy through confirmed infant status) for HIV-positive or STD-diagnosed pregnant women.

Methods

In 2003, the Bureau of STD, Florida Department of Health created the Mama Bear protocol that

prioritizes disease intervention services (DIS) for HIV-positive pregnant women and pregnant women diagnosed with an STD. The protocol requires DIS staff to connect with the client within 24 hours of receiving notification of her positive status and assist her to access HIV/STD treatment and prenatal care. The protocol requires the state laboratory to send an email notification to the local STD program whenever a positive HIV result is processed on a woman tested in the prenatal clinic of the county health department. The email notification system, termed a Mama Bear Alert, assures that the local STD staff knows immediately about the positive test result and can therefore act immediately to connect with the client.

Subsequently, St. Lucie County became the pilot site for an enhanced Mama Bear system that not only follows the intent of the original protocol, but also coordinates client services between multiple partners thus ensuring once a woman is contacted by DIS staff she and her infant are "hooked" into a streamlined and coordinated system nity agencies involved in the Core Group system are the STD program, the Targeted Outreach for Pregnant Women Act (TOPWA) program, HIV/AIDS Surveillance, the Healthy Changes and Healthy Start programs and Children's Medical Services (CMS). Core

Group partners may also identify an HIV-positive or STD newly diagnosed pregnant woman at any point during her pregnancy and bring her into the system. The goals of the partnership are to decrease duplication of services, decrease missed opportunities, maximize the use of agency resources, improve agency communication, assure client linkages and reduce negative birth outcomes (mortality and morbidity for the mother and infant).

The enhanced system utilizes a localized Mama Bear Alert system to notify the Core Group agencies that a new client has been identified. It also incorporates case conferencing to share client information and track her progress throughout the pregnancy and after delivery for the HIV-exposed newborn. Client case conferencing is facilitated by all parties signing HIPAA Business Associate Agreements (BAA) that allow the sharing of client information after she has signed a release with at least one of the participating agencies (the BAA template and guidelines will be provided). Changes made to the client referral/linkage system included a shift from the term “referral” (implying passive) to “linkage” (requiring verification, resulting in assurance), a review/redesign of client referral forms (consent, release of information, etc.), enhanced client assessments (economic/environmental issues which may influence client adherence to prescribed plan of care or access to appropriate services), improved client education about available services (a universal flyer was designed, and made available in English, Spanish and Creole), improved effectiveness in motivating clients to access services, and improved documentation of client referrals and linkages.

Results

In June 2003, the STD program, the TOPWA program, the Healthy Start program and CMS began monthly collaborative case conferences.

In the first 6 months, 35 HIV-positive clients were discussed. Six clients were newly diagnosed as HIV positive and had been reported to the STD program; 29 clients were known to be HIV positive prior to the current pregnancy and had been identified by one of the Core Group agencies. A total of 24 monthly collaborative case conferences among the 6 Core Group partners have occurred since project inception. The project has resulted in increased funding for the Healthy Changes program to provide intensive, specialized behavioral interventions (PCM); improved internal and external agency communication and collaboration; decreased duplication of client services; decreased missed opportunities; a maximized use of agency resources; assured client linkages; and reduced negative health outcomes. In the past 5 years, only 2 out of 89 infants from the project area have been diagnosed as HIV positive (2.3%).

Conclusions

Based on the results from the St. Lucie project, the Mama Bear enhanced protocol is now being replicated in many areas of the state. Making changes in community and agency bureaucracies is hard, yet necessary work. Leadership, persistence and commitment from all parties are necessary. Collaboration between key stakeholders is possible and ultimately pays off in pooled agency resources, decreased duplication of client services and reduced negative health outcomes. The next step for the St. Lucie project is to create a Mama Bear database that will allow the sharing of client electronic data between core internal and external (such as WIC, substance abuse treatment and obstetrics) parties. The database will be web-based (it will include a firewall), and will allow more effective process and outcome evaluation of the Mama Bear collaboration.